

National Health Care Network for children with oral clefts: organization, functioning, and preliminary outcomes

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ABSTRACT

Introduction. Oral clefts are major congenital anomalies that may affect the lip and/or palate, and that may also involve the nose and nostrils. In Argentina, their prevalence is approximately 15 per 10 000 births. In 2015, the Ministry of Health of Argentina created a national health care network for children with oral clefts in Argentina through the joint work with the National Registry of Congenital Anomalies (Red Nacional de Anomalías Congénitas, RENAC) (coordinating center for the national network) and the SUMAR Program. The objective of this study was to describe the health care network and its preliminary outcomes.

Population and methods. A total of 61 centers that provided a comprehensive treatment for oral clefts or in collaboration with other centers were identified and accredited. Maternity centers were connected with treating centers grouped in health care network nodes.

Results. In the period between March 2015 and February 2016, 550 newborn infants who were exclusively covered by the public health care system were identified. Among these, 18% had a cleft lip; 62%, cleft lip and palate; and 20%, cleft palate only; 75% were isolated cases and 25%, in association with other congenital anomalies.

Conclusion. Approximately 70% of children were assessed by a certified treating institution and are receiving treatment. The network seeks to improve data systematization, include the largest number of centers possible, strengthen interdisciplinary team work, and promote high-quality standards for treatments.

Key words: public health, networks, congenital anomalies, orofacial cleft.

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INTRODUCTION

In the past decades, a process known as epidemiological transition has taken place, which is characterized by a reduction in morbidity and mortality caused by malnutrition and infectious diseases and by a relative increase of morbidity and mortality caused by chronic and degenerative conditions.¹ The last category includes congenital anomalies (CAs), which are structural or functional alterations present at birth and that may be sporadic or inherited.²

These diseases affect the population's health conditions because they may cause chronic or disabling consequences and have a great impact on individuals and their families. In Argentina, the prevalence of major congenital structural anomalies (having severe medical and/or social consequences and requiring psychosocial support or treatment)³ is 1.53%⁴ and they account for 28% of infant deaths.⁵ In response to such problem, in 2009 Argentina created the National Registry of Congenital Anomalies (Red Nacional de Anomalías Congénitas, RENAC), which is dependent on the National Genetic Medicine Center (Centro Nacional de Genética Médica) and the National Administration of Labs and Health Institutes (*Administración Nacional de Laboratorios e Institutos de Salud*, ANLIS) and is a component of the Program for Uncommon Diseases and Congenital Anomalies (*Programa de Enfermedades Poco Frecuentes y Anomalías Congénitas*) established by the Ministry of Health. The RENAC covers the main maternity centers of Argentina and is made up of

neonatologists and pediatricians who detect and systematically report newborn infants (NBIs) with major CAs.⁶

Oral clefts (OCs) are major CAs that may affect the lip and/or palate, and that may also involve the nose and nostrils. Individuals affected by cleft lip and palate may have speech, hearing, swallowing, breathing, and physical appearance alterations and require care from an interdisciplinary team of health care providers since the antenatal period until approximately 18 years of life.^{7,8} OCs may occur in an isolated manner, in association with other CAs or as part of a syndrome. In Argentina, the prevalence of OCs is approximately 15 per 10 000 births. The most common OCs are cleft lip with or without cleft palate (12 per 10 000 births) whereas cleft palate is less common (3 per 10 000 births). Based on such prevalence, approximately 800 live births will be affected every year throughout the Argentina.⁹

Given the characteristics of this health problem and the required management, it is necessary to consider long-term consequences across all domains of children's daily lives and that of their families (social, psychological, bonding, financial aspects, etc.). The social context should

be considered an inherent part of every child's health status. For the purpose of favoring early referrals and a timely and high-quality care service for NBIs with OCs, the SUMAR Program contacted the RENAC in 2014 to coordinate a health care network for NBIs with OCs. The objective of this study was to describe the health care network and its preliminary outcomes.

MATERIAL AND METHODS

This was a descriptive, observational, and cross-sectional study. In this article we describe the activities conducted to implement the health care network and participating centers, by geographic distribution and type of care provided. Children affected by some type of cleft, associated CAs, place of residence, and antenatal detection were classified.

The following health care providers are part of the health care network: a) neonatologists or pediatricians working at the maternity centers and who detect NBIs affected by this anomaly; b) specialists working at the specialized treating centers and who are responsible for treatment and follow-up of affected children; c) members of the coordinating center for the health care network at RENAC (pediatricians, social worker, geneticists,

TABLE 1. Health care network services for newborn infants with oral clefts

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|--|
| Antenatal stage |
| Diagnostic ultrasound, antenatal care visit with the OC interdisciplinary team (1) and visit to the Psychology Department (1). |
| From 0 to 5 years old |
| First year of life |
| Report or notification of a NBI with OC for inclusion in the health care network, referral of NBI to the interdisciplinary team, initial assessment by the interdisciplinary team, visit to the Pediatrics Department (once a month), Pediatric Dentistry and Speech Therapy Departments (every two weeks), Specialized Surgery in OCs before and after the surgery (7), Otolaryngology Department (3), Nutrition Department (2), Psychology Department (once a month during the first year), Social Work Department (every three months), Physical Therapy Department (1), Genetics Department (1), Occupational Therapy Department (once a month), interdisciplinary team (before and after the surgery). Activities: impedance analysis (3), orthopedics before and after the surgery. Surgeries: nasolabial closure. Optimal time until first surgery: before 6 months old (180 days). |
| From 12 months to 5 years old |
| Visits to the specialists mentioned above; with the dentist, as of 3 years old. Hearing, speech therapy, post-surgery orthopedics, primary dentofacial orthopedics, video phonation, video nasoendoscopy, soft palate closure surgeries, primary pharyngoplasty, soft and hard palate closure, secondary pharyngoplasty, grommet placement. Optimal time until second surgery: before 1 year old. |
| From 6 to 9 years old |
| Visits to the Pediatrics, Pediatric Dentistry, Speech Therapy, Psychology, Social Work, Specialized Alveolar Cleft Lip and Palate Surgery, Nutrition, Otolaryngology Departments and with the OC interdisciplinary team. Activities: speech therapy, mixed dentofacial orthopedics, panoramic X-ray, video phonation and video nasoendoscopy, bone graft and velopharyngeal surgery. |
| From 10 to 15 years old |
| Visits to the Pediatrics, Pediatric Dentistry, Speech Therapy, Psychology, Social Work, Specialized OC Surgery, Nutrition, Otolaryngology Departments and with the OC interdisciplinary team. Activities: speech therapy, permanent orthodontics, panoramic X-ray, video phonation and video nasoendoscopy, cephalometric lateral telerradiography, bone graft and velopharyngeal surgery. |

OCs: oral clefts; (n): number of visits; NBI: newborn infant.

epidemiologists); d) management team of the SUMAR Program at a national level and of the jurisdictional management units.

After consulting experts during 2014, a health care plan was designed considering quality and opportunity criteria in the care process provided to children with OCs; it included different services (Table 1). Compliance with the different stages of the health care process is verified through a series of reports sent by the network providers to the coordinating center. The first report, made at the level of maternity centers, consists of a notification or report of NBIs with OCs in the first 48 hours after birth. This triggers a referral process of NBIs to an accredited treating center, based on their family's place of residence and the severity of their health status. Once a child has an appointment and is seen by the treating center, the center confirms diagnosis and establishes a follow-up plan, reflected in subsequent reports. The specialties considered basic for OC care are dentistry, speech therapy, and surgery. Although teams made up of these three specialties and in accordance with the characteristics of the management required for this pathology are considered "complete," the network includes health care providers from other specialties

(pediatrics, otolaryngology, social work, nursing, psychology, genetics, cardiology, etc.).

Treating centers were accredited in advance at the level of each jurisdiction and by the Ministry of Health of Argentina. For analysis purposes, centers were classified into four groups: 1) centers with a complete team, including the three specialties considered basic; 2) centers that did not offer the three basic specialties but complemented their team with providers from a different accredited local center; 3) centers that did not offer the three basic specialties but complemented their team with providers from a different accredited center from another town; 4) centers that did not offer the three basic specialties and did not complement their team with providers from the same jurisdiction. For network functioning purposes, treating centers were grouped into nodes, which sent reports to the coordinating center.

In this study, a case was defined as a NBI with cleft lip, cleft lip and palate, and cleft palate, in association or not with other CAs, born between March 1st, 2015 and February 29th, 2016 and who was alive at the time of reporting to the RENAC. Stillbirths or infants deceased before reporting and those who had health coverage through a social

TABLE 2. *Activities of the health care network for children with oral clefts*

Organization of the health care network

- A formal alliance was celebrated between the RENAC y the SUMAR Program.
 - Health care providers joined the RENAC as part of the health care network coordination.
 - Treating centers for children with OCs were identified and accredited by national and jurisdictional authorities.
 - The health care network coordinating center and the 24 jurisdictional management units of the SUMAR Program came into contact to share strengthening strategies of intraprovincial networks.
-

Design of detection and follow-up of children with oral clefts

- With the advice of specialists in these anomalies, a specific and stepwise health care service plan was established and designed together with the SUMAR Program.
 - A series of reports were made corresponding to the detection, referral, diagnosis, and treatment stages.
-

Health care providers' training

- An operational manual was developed to upload reports to the RENAC's website, together with an online video.
 - Face-to-face and online training sessions were held for neonatologists and other health care providers from the treating centers. Neonatologists were instructed to report NBIs with OCs in the first 48 hours after birth.
-

Detection and referral of newborn infants with oral clefts

- All stages, i.e. detection, referral, diagnosis, and treatment, were monitored.
 - As neonatologists reported cases, the coordinating center contacted the teams at the treating centers and scheduled an initial appointment with the families.
 - In some specific, more complex situations, the coordinating center contacted the families to ensure their access to treating centers and treatment adherence, in interaction with health care teams.
 - In order to promote compliance with the schedule of appointments to see the specialists, a "Family Appointment Book" was designed and handed to each family by neonatologists before discharge from the maternity center or by teams at the treating centers.
-

insurance program or a managed care organization were excluded because they were not part of the target population of the SUMAR Program.

RESULTS

The activities carried out to organize the health care network for children with OCs are described in *Table 2*. The network is made up of 146 maternity centers from the public subsector and 61 accredited treating centers from across the country. Among the latter, 33 (54.1%) have a complete team working there; 18 (29.5%) are complemented by providers from other local centers; 8 (13.1%) are complemented by providers from centers located in a different town; and 2 (3.3%) do not provide services from the three specialties and are not complemented by other providers from the same jurisdiction (Chaco and Tucumán) (*Table 3*). Tierra del Fuego was the only jurisdiction where there was no accredited

treating center. Treating centers are grouped into 39 network nodes; of these, 29 (74%) sent reports regularly and the other 10 (26%) centers did not report their activities to the coordinating center in the study period. Maternity centers from all jurisdictions reported cases except for Tierra del Fuego, where there were no NBIs with OCs in the study period (*Table 4*).

A total of 550 live NBIs had OCs; of these, 98 (18%) had cleft lip; 339 (62%), cleft lip and palate; and 113 (20%), cleft palate. A total of 414 NBIs had isolated OC; 135, OC associated with other CAs; and for 1 case it was not specified whether it was isolated or in association with other CAs. Isolated OCs were detected by antenatal ultrasound in 81/414 (20%) cases, and OCs associated with other CAs, in 39/135 (29%) cases.

Out of the 550 NBIs with OCs, 46 (8%) were in poor clinical condition to be referred

TABLE 3. Maternity centers and accredited health care centers for the management of oral clefts by jurisdiction

| Jurisdiction | Maternity centers | Accredited centers for the management of OCs | | | | Network nodes | | |
|---------------------|-------------------|--|--|--|---|---------------|---------|-------------------------------------|
| | | All basic | Not all basic specialties | | | Total | Totales | Reported to the coordinating center |
| | | | Basic specialties in different local centers | Basic specialties in different centers from another town | Not all basic specialties and no complementation with a different center in the same jurisdiction | | | |
| Buenos Aires | 50 | 6 | 4 | 0 | 0 | 10 | 7 | 6 |
| CABA | 12 | 2 | 1 | 0 | 0 | 3 | 3 | 0 |
| Catamarca | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| Chaco | 4 | 0 | 0 | 0 | 1 | 1 | 1 | 1 |
| Chubut | 5 | 2 | 0 | 0 | 0 | 2 | 2 | 2 |
| Córdoba | 10 | 2 | 3 | 0 | 0 | 5 | 2 | 1 |
| Corrientes | 4 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| Entre Ríos | 5 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| Formosa | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| Jujuy | 4 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| La Pampa | 2 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| La Rioja | 2 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| Mendoza | 5 | 2 | 1 | 0 | 0 | 3 | 2 | 2 |
| Misiones | 5 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| Neuquén | 6 | 1 | 0 | 4 | 0 | 5 | 1 | 1 |
| Río Negro | 5 | 3 | 0 | 1 | 0 | 4 | 3 | 2 |
| Salta | 3 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| San Juan | 1 | 0 | 3 | 0 | 0 | 3 | 1 | 1 |
| San Luis | 2 | 1 | 0 | 0 | 0 | 1 | 1 | 0 |
| Santa Cruz | 3 | 2 | 0 | 0 | 0 | 2 | 2 | 0 |
| Santa Fe | 9 | 2 | 6 | 3 | 0 | 11 | 3 | 2 |
| Santiago del Estero | 1 | 1 | 0 | 0 | 0 | 1 | 1 | 1 |
| Tierra del Fuego | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Tucumán | 4 | 0 | 0 | 0 | 1 | 1 | 1 | 1 |
| Total | 146 | 33 | 18 | 8 | 2 | 61 | 39 | 29 |

OCs: oral clefts; CABA: Autonomous City of Buenos Aires.

to treating teams because of the following causes: prematurity, low birth weight, and coexistence of severe major anomalies (i.e., life-threatening anomalies and those requiring priority treatment). Among the remaining 504 NBIs, 28 (6%) were referred from the maternity center to non-accredited centers and 476 (94%) were referred to the centers accredited by the network. According to reports received by the coordinating center, 332/476 children (70%) were assessed and started a treatment and follow-up plan; of these, 286 (86%) were old enough to have the surgery in the study period. At the time, 41% of these children have already undergone surgery (116/286), whereas the rest are still in follow-up (Figure 1). Among children who had surgery, their median age at the time of the first surgery was 197 days. In the period between birth and the first surgery, children had an average of 7 visits to the Dentistry Department, 5 to the Speech Therapy Department, and 3 to the Surgery Department (pre-surgery visits). An average of 5 visits were made to the pediatrician. In relation to cases referred to other specialties for assessment, 231/332 (70%)

were referred to the Cardiology Department; 188 (57%), to the Genetics Department; 195 (59%), to the Psychology Department; 160 (48%), to the Nutrition Department; and 216 (65%), to the Social Work Department.

DISCUSSION

This study describes the Argentine health care network for NBIs with OCs, coordinated by the RENAC since it was launched in March 2015. The RENAC is a preexisting CA surveillance system that systematically monitors variations in CA prevalence and conducts research on their causes.^{9,10} The health care network is the result of one of the RENAC's extended goals: helping patients and their families to access health care services and genetic counseling.¹¹ It is important to consider that reporting and referral deadlines for NBIs with OCs in the first 48 hours after birth have altered the monthly reporting routine to the RENAC. This was a challenge for the surveillance system, which introduced new participants –teams working at the treating centers– and required a greater effort from health care providers at the maternity centers.

TABLE 4. Newborn infants with oral clefts detected by the National Registry of Congenital Anomalies by jurisdiction of residence, based on the type of cleft and clinical presentation, between March 1st, 2015 and February 29th, 2016

| Jurisdiction | Total number of reported patients (n) | Type of oral cleft | | | Clinical presentation | |
|---------------------|---------------------------------------|--------------------|----------------------|--------------|-----------------------|---------------------------------|
| | | Cleft lip | Cleft lip and palate | Cleft palate | Isolated | Associated with other anomalies |
| Buenos Aires | 172 | 36 | 97 | 39 | 129 | 43 |
| CABA | 18 | 2 | 11 | 5 | 15 | 3 |
| Catamarca | 7 | 2 | 5 | 0 | 7 | 0 |
| Chaco | 34 | 4 | 23 | 7 | 26 | 8 |
| Chubut | 7 | 0 | 4 | 3 | 5 | 2 |
| Córdoba | 26 | 1 | 17 | 8 | 16 | 10 |
| Corrientes | 20 | 2 | 12 | 6 | 19 | 1 |
| Entre Ríos | 16 | 4 | 8 | 4 | 11 | 5 |
| Formosa | 15 | 0 | 12 | 3 | 12 | 3 |
| Jujuy | 13 | 4 | 7 | 2 | 7 | 6 |
| La Pampa | 3 | 1 | 2 | 0 | 2 | 1 |
| La Rioja | 5 | 0 | 5 | 0 | 4 | 1 |
| Mendoza | 36 | 9 | 23 | 4 | 31 | 5 |
| Misiones | 24 | 6 | 15 | 3 | 17 | 7 |
| Neuquén | 11 | 5 | 4 | 2 | 4 | 7 |
| Río Negro | 4 | 0 | 4 | 0 | 3 | 1 |
| Salta | 39 | 9 | 20 | 10 | 25 | 14 |
| San Juan | 16 | 3 | 8 | 5 | 13 | 3 |
| San Luis | 7 | 2 | 5 | 0 | 5 | 2 |
| Santa Cruz | 2 | 0 | 2 | 0 | 2 | 0 |
| Santa Fe | 27 | 4 | 18 | 5 | 21 | 6 |
| Santiago del Estero | 27 | 3 | 20 | 4 | 26 | 1 |
| Tucumán | 21 | 1 | 17 | 3 | 15 | 6 |
| Total | 550 | 98 (18%) | 339 (62%) | 113 (20%) | 414 (75%) | 135 (25%) |

CABA: Autonomous City of Buenos Aires.

A similar experience has been in place in Chile since 2005, when OCs were included in the Explicit Health Guarantees System, which guarantees and organizes care for certain diseases.¹² In Chile, health care is organized into 9 surgery centers selected based on specialization, geographic, and infrastructural criteria, which meet health care demands since birth until 15 years old.¹³

In the United Kingdom, health care concentrated into 11 centers with multidisciplinary teams working in accordance with high-quality standards. A study conducted in the United Kingdom showed that treatment results had improved based on the introduction of centralized multidisciplinary services.¹⁴

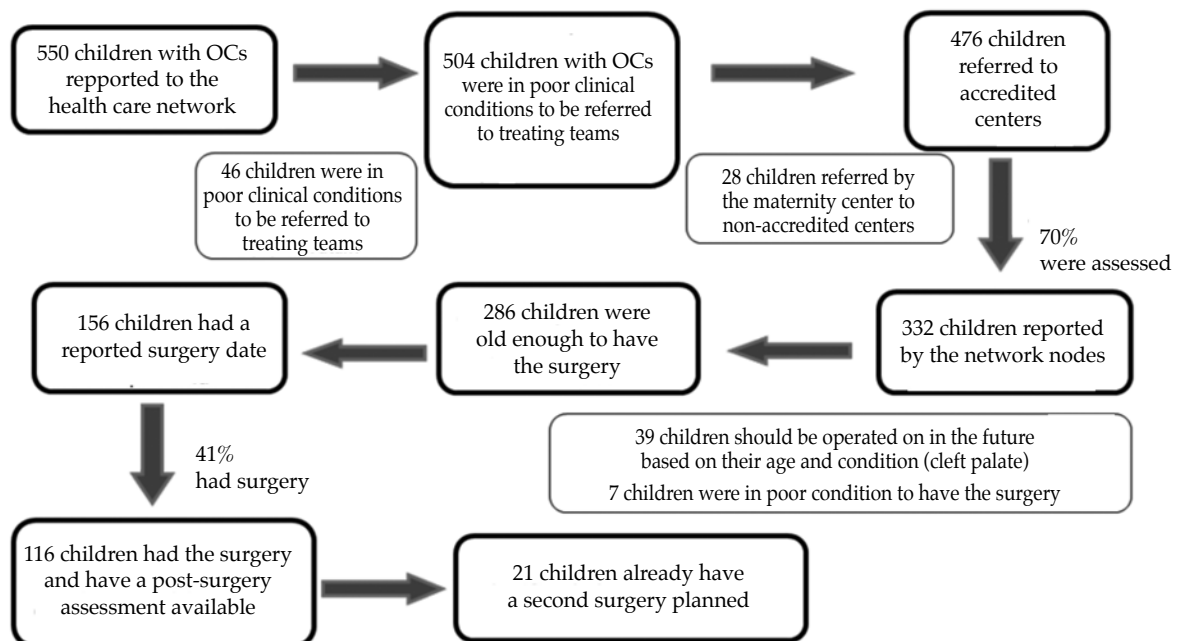
In Argentina, a very important precedent is that of the Argentine Society of Plastic, Cosmetic and Reconstructive Surgery (Sociedad Argentina de Cirugía Plástica, Estética y Reparadora, SACPER), which has worked at a national level for the diagnosis and interdisciplinary treatment of patients with OCs and for the standardization and promotion of regional health care.^{15,16} A prior study conducted in Argentina in 970 patients showed that 43.5% of them lacked health insurance coverage and 41% did not have the financial resources to pay for treatment. In the

same study, it was observed that 30% of patients lived more than 2 hours away from the health care center.¹⁷

Similarly to the health care network for OCs, another Argentine precedent is the National Heart Disease Program (Programa Nacional de Cardiopatías Congénitas, PCC), which was launched in 2010 and has favored access to surgeries, a reduction in waiting lists, and health care service regionalization. In addition, since 2013, the Tertiary Care Perinatal Package (Paquete Perinatal de Alta Complejidad, PPAC) has promoted access to surgical treatment for NBIs with hydrocephalus, spina bifida, gastroschisis, omphalocele or intestinal atresias. As these two initiatives seek to reduce infant mortality due to these causes, the health care network for OCs was organized to minimize their impact on morbidity. OCs are not life-threatening but require a multidisciplinary long-term management, which may have functional, morphological, and aesthetic sequelae, depending on the severity of the anomaly, especially in relation to accessing a timely and high-quality care service.

The network's organization in Argentina started with the identification of health care providers or teams specialized in OCs available across the national territory. A survey conducted

FIGURE 1. Flow chart of the health care process for patients with oral clefts detected at maternity centers



OCs: oral clefts.

in 2011 by the School of Economic Sciences of Universidad Nacional de La Plata –coordinated with the specialists of the School of Medical Sciences– assessed the services offered by the public sector for OC management. This study revealed that each jurisdiction resolved health care in a fragmented and informal manner, with scarce population nominalization, without an organized network and with referrals made without counter-referrals.

The conclusions proposed that, given the complexity of this condition, it was necessary to coordinate health care providers into a structure that guaranteed a timely and practically comprehensive treatment, which would minimize costs and be medically effective.¹⁸

The results of this study show that, first of all, maternity centers and treating centers were brought together. Out of all NBIs detected in the maternity centers, a high percentage (94%) were referred to the networks' providers and approximately 70% started a treatment and follow-up plan. More than 100 children had a surgery; in addition, they had access to visits to different specialists. Among operated patients, the time elapsed until the first surgery was close to an optimal 180-day period. In relation to the epidemiological profile of detected patients, the most common anomaly was cleft lip and palate (62%) and the isolated presentation (75%), which was consistent with what has been reported in the bibliography.^{8,19} A low rate of antenatal detection was observed, which coincides with what has been reported before for Latin America,²⁰ although other regions show higher detection rates.²¹

The study conducted in this period has certain limitations. The initial accreditation process for treating centers was carried out by the provincial health authorities and were validated by the National Board of Health Regulations and High-Quality Health Care Services. Some centers were accredited in the field during 2016 and 2017 by the SUMAR Program, and different health care modalities and scarce registries of multidisciplinary treatment were observed. Many centers have not been assessed yet, and treatment protocols have not been compared to those existing in the network; besides, the different therapeutic results have not been assessed. The American Cleft Palate-Craniofacial Association (ACPA), a supranational organization that groups members from 60 countries and more than 30 health care fields, published standards

for the classification and accreditation of treating teams in the United States and Canada.²² To our knowledge, in Argentina, no similar standards have been published, so the international standards could be adapted and Argentine standards adequate for the local context should be defined.

Specific training sessions are planned for the purpose of harmonizing procedures and improving teams' expertise. Treating centers have been detected that are not part of the network yet. Their inclusion will allow to complete certain aspects of treatment closer to the families' homes and coordinate them with the interdisciplinary team of each jurisdiction. In addition, uploading reports is an arduous task for health care teams so it has been decided to incorporate the Argentine Integrated Health Care Information System (Sistema Integrado de Información Sanitaria Argentino, SISA) to the network. SISA offers a more dynamic data uploading and follow-up information organization for each patient as a unified registry, facilitating coordination among the centers involved in treatment.

CONCLUSION

Advances have been made in the creation and consolidation of a national health care network for OCs that cover the detection, timely referral, and follow-up of children and involves multiple health care providers and interconnected centers from the 24 jurisdictions of Argentina. The following is still pending: the accreditation of some centers that have not yet been included in the network, transferring the data registration system to SISA to facilitate data follow-up, strengthening interdisciplinary work, and fostering training to promote common work leading to high-quality standards in health care. ■

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REFERENCES

1. Frenk J, Frejka T, Bobadilla J, et al. La transición epidemiológica en América Latina. *Bol Oficina Sanit Panam* 1991;111(6):485-96.
2. Asamblea Mundial de la Salud, 63. Defectos congénitos: informe de la secretaría. Ginebra: Organización mundial de la Salud; 2010. [Accessed on: August 23th, 2017]. Available at: http://apps.who.int/iris/bitstream/10665/4849/1/A63_10-sp.pdf.

3. Stevenson R, Hall J, Goodman R. Human malformation and related anomalies. Oxford Monographs on Medical Genetics. New York: Oxford University Press; 1993.
4. Liascovich R, Barbero P, Groisman B, et al. RENAC 2016. Reporte anual 2016. Análisis epidemiológico de las anomalías congénitas en recién nacidos, registradas en el año 2015 en la República Argentina. Buenos Aires: Ministerio Salud de la Nación; 2016. [Accessed on: February 20th, 2017]. Available at: http://www.msal.gov.ar/images/stories/bes/graficos/0000000924cnt-reporte_renac_2016.pdf.
5. Dirección de Estadísticas e Información de Salud. Estadísticas Vitales, Información Básica 2015. Buenos Aires: Ministerio de Salud; 2016. [Accessed on: February 10th, 2017]. Available at <http://www.deis.msal.gov.ar/wp-content/uploads/2016/12/Serie5Numero59.pdf>.
6. Groisman B, Bidondo MP, Barbero P, et al. RENAC: Registro Nacional de Anomalías Congénitas de Argentina. *Arch Argent Pediatr*. 2013;111(6):484-94.
7. Habel A, Sell D, Mars M. Management of cleft lip and palate. *Arch Dis Child* 1996;74(4):360-6.
8. Mossey P, Little J, Munger R, et al. Cleft lip and palate. *Lancet* 2009;374(9703):1773-85.
9. Bidondo MP, Groisman B, Gili J, et al. Prevalencia de anomalías congénitas en Argentina y su potencial impacto en los servicios de salud. *Rev Argent Salud Pública* 2014;5(21):38-44.
10. Groisman B, Gili J, Giménez L, et al. Geographic clusters of congenital anomalies in Argentina. *J Community Genet* 2017;8(1):1-7.
11. Groisman B, Bidondo MP, Barbero P, et al. La Red Nacional de Anomalías Congénitas (RENAC): objetivos ampliados de la vigilancia. *Arch Argent Pediatr* 2016;114(4):295-7.
12. Cordero Carrasco E, Correa Hernández S, Pantoja Parada R. Prevalence of Patients with cleft lip and palate who were treated at the San Borja Arriarán Clinical Hospital in Santiago Chile, within the AUGE healthcare Plan. *Int J Odontostomat* 2015;9(3):469-73.
13. Chile. Ministerio de Salud. Guía clínica de Fisura labio palatina. Santiago: MinSal; 2009. [Accessed on: February 10th, 2017]. Available at: <http://web.minsal.cl/portal/url/item/7220f6b9b01b4176e04001011f0113b7.pdf>.
14. Ness AR, Wills AK, Waylen A, et al. Centralization of cleft care in the UK. Part 6: a tale of two studies. *Orthod Craniofac Res* 2015;18(Suppl 2):56-62.
15. Normatización de tratamiento FLAP. *Rev Argent Cir Plást* 2007;13(1):41-3.
16. Mogliani M. Doce años de la creación del Centro de referencia y contrarreferencia nacional para el tratamiento de niños con fisura labio nasolabioalveolar y malformaciones asociadas. *Rev Argent Cir Plást* 2013;19(4):108-11.
17. Andrade J, Chuit R, Consoli N, et al. Análisis Epidemiológico de 970 pacientes con fisuras labio alveolo palatina con tratamiento prequirúrgico. *Bol Acad Nac Med B Aires* 2009;87(2):261-72.
18. Garriga M, Rosales W. Atención de malformaciones y deformaciones congénitas: Fisura labio alvéolo palatina - Displasia de desarrollo de cadera - Pie equino varo congénito. In: Saligno M, Silva H, Zerbino M, et al, eds. Lecciones aprendidas y desafíos futuros bajo nuevos esquemas de gestión de la salud en la Argentina: la experiencia conjunta Plan Nacer y SUMAR Program del Ministerio de Salud de la Nación y Facultad de Ciencias Económicas de la Universidad Nacional de la Plata, UNLP. Buenos Aires: MINSAL-SUMAR Program-UNLP, 2014. [Accessed on: April 17th, 2017]. Available at: <http://www.msal.gov.ar/sumar/images/stories/pdf/lecciones-aprendidas-desafios-futuros.pdf>.
19. Dixon M, Marazita M, Beaty T, et al. Cleft lip and palate: synthesizing genetic and environmental influences. *Nat Rev Genet* 2011;12(3):167-78.
20. Campaña H, Ermini M, Aiello HA, et al. Prenatal sonographic detection of birth defects in 18 hospitals from South America. *J Ultrasound Med* 2010;29(2):203-12.
21. Steinberg JP, Gosain AK. Thirty Years of Prenatal Cleft Diagnosis: What have we learned? *Plast Reconstr Surg* 2015;136(3):550-7.
22. Strauss RP. Cleft palate and craniofacial teams in the United States and Canada: a national survey of team organization and standards of care. The American Cleft Palate-Craniofacial Association (ACPA) Team Standards Committee. *Cleft Palate Craniofac J* 1998;35(6):473-80.